

Comments on Proposed Revisions to Mandatory Guidelines for Federal Workplace Drug Testing Programs

Agency Name: Substance Abuse and Mental Health Services Administration
Docket Number: 04-7984

Referenced Document Title: Proposed Revisions to Mandatory Guidelines for Federal Workplace Drug Testing Programs

The following are my comments on the proposed revisions to drug testing guidelines SAMHSA is proposing. I serve on the International Paruresis Association's (IPA) Board of Directors, but the following comments are my own and do not represent the opinions of the IPA. They are to be considered as personal comments, separate from IPA's formal response to the regulation, of which I was a contributor. My capacity within IPA is to lead a support group in my community, act as co-facilitator at recovery workshops, provide expertise on the recovery process to the organization, and assist with the organization's goals as my talents and energies permit.

The comments IPA provided are specific recommendations addressing the regulation. My comments are intended to reflect the human side of urine drug testing programs and do not directly address specific guidelines. Rather, they provide a picture of the impact of current test guidelines on people and will hopefully serve to guide the rulemaking process to be more fair and open to people with paruresis or other diseases that affect the process of urination.

Paruresis, also known as shy bladder, affects the ability of people to urinate in the presence of others -- especially in situations where the circumstances can produce anxiety in the sufferer. Situations such as crowded restrooms, waiting in line, or evaluation of a person as occurs at a doctor's office or drug test are places where a person with paruresis experiences difficulty. It is not unlike the jitters a person feels when speaking before a large audience, but it affects the person's bladder instead. I believe it is a disease that people cannot control until it reaches the point of significant disruption to one's life. At that point, people sometimes seek help, but many instead alter their lives in a cycle of increasing isolation in a mistaken attempt to try to cope with it. Paruresis is progressive. Trying to avoid public restrooms or change one's career to avoid facing a random or pre-employment drug test often leads to the condition worsening, and to more extreme forms of isolation such as avoiding social engagements and in the worst cases, becoming housebound.

Rather than speaking in abstract terms, I would like to tell you my own experience with this disease, which started early in life and stretched well into my adulthood. I don't remember any triggering incident that led to the problem developing, but as a student in elementary school I remember that I didn't use the restrooms there very much. In high school, I remember being unable to use the urinals in the restrooms and made some attempts to force myself to stand there and try. I was unsuccessful. I ended up trying to

cope by restricting my intake of fluids during those years and only using the bathroom at home. Fortunately, I didn't experience any serious health consequences such as dehydration or heatstroke after gym class on a hot day. I wasn't very active socially in high school because I was reluctant to face the crowded restroom situations at dances or ball games. As a student, I felt isolated and alone. Those were not good years for me. If it weren't for this condition, I would have had a very different and far more active, even fun, experience in high school.

I mention these experiences as a student because urine-based drug testing is starting to find its way into schools for both those participating in athletic teams and also for the general student population as a way of reducing illegal drug use. While it may be worthwhile to pursue these goals, doing it through a urine test could cause serious hardship to a student with paruresis. For a young person who lacks the adult emotional development to rationally deal with being unable to provide a urine sample for a drug test, the prospect of being ridiculed by school personnel or peers would be an extremely traumatic event. At the very least it could lead to students not participating in activities that would be most valuable for their social development. At the worst, it could lead to severe embarrassment and even to suicide. This is because people with paruresis hide the condition from others because it is so personal in nature. They often think they are the only ones with the problem and use words such as "crazy," "strange," or "weird" to describe how they view themselves. These are very common statements we hear from people who come to IPA's online Internet forum or recovery workshops. In high school I tried my best to ignore thoughts that I was strange, or worse, but they were always in the back of my mind when I wanted to use a restroom there.

Drug testing for youth in schools, if done at all, should be undertaken in way that is sensitive to the needs of youth in that situation. It should not lead to embarrassment or ridicule, it should be completely private and confidential, and people with paruresis cannot be treated in a way that is demeaning, suspicious, or denies them participation in school activities. Note that I am commenting on the *process* of drug testing, and not on the consequences of proven drug use, which is a completely different matter.

Students should be offered several different options at the time of the test, and there should be no enforcement of a "preferred" or "primary" method, because if urine is the preferred method, people with paruresis will feel singled out by needing to select a method that treats them differently from everyone else. If only a few people choose a non-urine test, test monitors may be suspicious of the student in some way. In other words, a nurse or other test monitor should tell the student, "You can choose a urine test, saliva test, hair test, etc." The choice should be left up to the student and no one else. As much anonymity as possible should be built into the sample collection process. While I cannot comment on exactly how to do this because I'm not an expert, I do think that the kind of sample a student chooses should be known to as few people as possible, and it should not be known to school administrators or other students, only to the collector. Samples should be numbered so that lab personnel are not aware of a student's name when analysis is conducted.

Sample collection for student drug testing can also be a time to offer literature on paruresis, in a standard information packet that is supplied to all students being tested. This approach would allow a student to become aware that paruresis is a disease that can be treated successfully and would offer them an opportunity to seek treatment early in life when it is fastest, most effective, and least expensive.

After completing high school I entered a local college, partly because I could live at home and deal with paruresis in the same way I did in high school. I might have lived away from home and had a better choice of colleges if I didn't need to deal with what was still a secret problem I had told no one about. I did well in college and was able to get a job with a good employer. When I graduated from college it was in the early 1980s and at that time there was no drug testing for most private-sector jobs. Today, as a person graduating from college I would face drug testing for most corporate and government employment, and might decide to work as a self-employed person or at a very small company in order to avoid a urine drug test. Here again is another situation where paruresis can discriminate against a talented person who is eminently qualified for a job, but unable to provide a urine sample.

I know of only a few jobs that call for the ability to urinate in the presence of other people as a requirement for employment. Certainly it's not a requirement for an accountant or an engineer. It might be one for a tour guide who takes groups of people out into the desert where there are no restrooms available and no place to hide. But for the rest of us, it seems to be absurd to include "ability to urinate into a cup with a monitor directly witnessing this or standing outside of a stall door" as a necessary requirement for employment. This seems to be a significant change in employment law that happened without proper debate of something so fundamental. Many might take such a change for granted, but for people with paruresis it is a wholesale denial of a huge number of potential career options that were available to them only a few years ago before widespread adoption of urine-based drug testing. It is a change that I see as similar to requiring all people to be fingerprinted before employment, or to pass a polygraph test.

By far the most egregious part of current regulations is the allowance of a person who cannot provide a urine sample to be denied employment, without concrete evidence, as if they were a drug user. There needs to be a clear distinction between the *inability* to provide a urine sample, and the *refusal* to provide any kind of sample that could be used to test for drug use. Inability to provide a urine sample does not constitute guilt, nor does it even constitute suspicion of drug use. It simply means a person can't urinate under the circumstances when the test is given and this could happen for many reasons, including paruresis. If a person refuses to provide any kind of sample after being offered several different alternatives, then that might be a situation where suspicion of drug use is warranted.

Many employers today are practicing wanton discrimination against people with paruresis by refusing them a job because they cannot provide urine for a drug test. People with

paruresis are entitled to employment as long as they meet the requirements of the job and pass the interview process. If one of the requirements of the job is that they don't use illegal drugs, then inability to provide a urine sample must not be equated with drug use. There is no logical connection between the two, only an assumed connection with no basis in fact.

When I graduated from college I found a job with a good employer, a large company with an excellent health insurance benefit. I was finding that my paruresis was worsening, and around five years after I joined the company I sought treatment. At that time very little was known about the disease, but I was able to get some relief from it. Around this time my employer started to do urine-based drug testing of new employees, and other companies were starting to do it as well. I began to feel trapped in my job, realizing that if I wanted to quit I might be unable to provide urine samples to find another one. I spent a lot of time worrying about how to deal with that situation should I be laid off or wanted to leave the company for a different job. I ended up working there for eleven years, and passed up several excellent opportunities elsewhere because I still was having trouble providing urine samples at medical checkups. I figured that if I had trouble at my own doctor's office, I would certainly have trouble in a situation where my career was at stake applying for work at a new employer.

Compared to many people I have met through IPA, I was lucky. Because I was in a good job and not subject to drug testing, I was able to advance my career. I had health insurance, so I could afford treatment. Staying at the same employer was perceived as loyalty, but even at my employer I turned down some opportunities that demanded extensive travel and other situations where the restroom facilities might be unpredictable. Now that drug testing is widespread people with paruresis tend to choose jobs that don't have a drug test requirement, or opt for self-employment. Our economy is not benefiting from the skills of many talented workers simply because these workers face rejection of their job application if they cannot provide a urine sample. Some people have lost their jobs when random drug testing was implemented for all employees in a company. Families have been affected by sudden loss of a job, and in a particular case IPA is pursuing in court there was wrongful denial of unemployment benefits to an employee because failure to provide a urine sample was equated with drug use.

Can you imagine what can happen to a person today who graduates from college with paruresis? If they cannot provide a urine sample for employment they will be denied a job, and without health insurance they cannot afford treatment. Current treatment for paruresis costs several thousand dollars and consists of workshop participation, physician exams, a series of appointments with a psychologist skilled in treatment, and for some people, a course of expensive prescription medications that may last a year or more. Even with many advances we have made, cure rates are still quite low and a person is not guaranteed they will recover. In my particular case, well over \$20,000 was spent in order to recover, partly because treatment methods were poorly understood when I first sought help. But many people today will face at least \$2,000 to \$5,000 in expenses for treatment with an uncertain outcome. If a graduating student becomes self-employed or takes a job

below their skill level in order to survive, they will be unable to afford effective treatment and will be locked into a Catch-22 kind of situation where they are trained and qualified for a job, but unable to get the job because they cannot afford the treatment to recover from an unrelated medical problem.

Only a few years ago after great personal effort and research, I was able to make a full recovery from paruresis. I learned about IPA during that time and decided to become an active participant in the organization. Since I joined them I have met a great many kind, intelligent, capable people who are dealing with this disease. In the short time our organization has been around, urine-based drug testing has been rapidly adopted in the United States and it has risen to be one of the top issues IPA is struggling with. I have personally met many people whose lives have been adversely affected by the current state of urine drug testing regulations. I feel very strongly that they must be re-thought to eliminate discrimination against people who have difficulty providing a urine sample. I want to devote my time and effort toward finding a cure for this disease, and short of major government funding, the best thing our government could do for IPA and the millions of people with paruresis is to provide fair and equitable regulations for employment drug testing so the people in my organization can focus on finding a cure and reducing the cost for those who seek treatment.

I want to thank SAMHSA for the opportunity to provide comments on these regulations, and offer my assistance at any time should you have questions about how to better accommodate the needs of people with paruresis.

Respectfully Submitted,

Chris Carvalho
Member, IPA Board of Directors

International Paruresis Association
PO Box 65111
Baltimore, MD 21209
Tel: (800) 247-3864